



END OF LIFE CARE BIBLIOGRAPHY JANUARY 2003

1: Am J Hosp Palliat Care 2002 Nov-Dec;19(6):367-8

Comment on:

Am J Hosp Palliat Care. 2002 Nov-Dec;19(6):426-30.
Constipation revisited.

Enck RE.

Publication Types:

Comment

Editorial

PMID: 12442967 [PubMed - indexed for MEDLINE]

2: Am J Hosp Palliat Care 2002 Nov-Dec;19(6):372

Comment on:

Am J Hosp Palliat Care. 2002 Jul-Aug;19(4):263-6.

Lack of knowledge and training affects quality of hospice care for persons with dementia.

Kirchhoff M.

Publication Types:

Comment

Letter

PMID: 12442969 [PubMed - indexed for MEDLINE]

3: Am J Hosp Palliat Care 2002 Nov-Dec;19(6):376-80

Communicating with surrogate decision-makers in end-of-life situations:
substitutive descriptive language for the healthcare provider.

Limerick M.

University of Texas at Austin, USA.

This article discusses the manner and actual wording used by healthcare providers in communicating difficult information as it relates to end-of-life discussions. Several examples are given and substitutive language is suggested for more effectively obtaining informed consent from surrogate decision-makers, who are often responsible for determining the course of care for the terminally ill.

PMID: 12442971 [PubMed - indexed for MEDLINE]

4: Am J Hosp Palliat Care 2002 Nov-Dec;19(6):381-6

Use of aromatherapy with hospice patients to decrease pain, anxiety, and depression and to promote an increased sense of well-being.

**Library Program Office
Office of Information**
Veterans Health Administration

Louis M, Kowalski SD.

Department of Nursing, University of Nevada, Las Vegas, USA.

This study measured the responses of 17 cancer hospice patients to humidified essential lavender oil aromatherapy. Vital signs as well as levels of pain, anxiety, depression, and sense of well-being were measured (using 11-point verbal analogs). Each subject was measured on three different days before and after a 60-minute session consisting of (1) no treatment (control); (2) water humidification (control); or (3) 3-percent lavender aromatherapy. Results reflected a positive, yet small, change in blood pressure and pulse, pain, anxiety, depression, and sense of well-being after both the humidified water treatment and the lavender treatment. Following the control session (no treatment), there was also slight improvement in vital signs, depression, and sense of well-being, but not in pain or anxiety levels.

PMID: 12442972 [PubMed - indexed for MEDLINE]

5: Am J Hosp Palliat Care 2002 Nov-Dec;19(6):426-30

Comment in:

Am J Hosp Palliat Care. 2002 Nov-Dec;19(6):367-8.

Presence and severity of constipation in hospice patients with advanced cancer. McMillan SC.

University of South Florida, College of Nursing, Tampa, USA.

Although constipation is a problem commonly seen in hospice patients it is not often addressed in the literature as a target symptom needing management. The purpose of this study was to assess the levels of self-reported constipation in a group of patients with advanced cancer at admission to hospice and two weeks and one month after admission. The constipation assessment scale (CAS) measured the presence and intensity of constipation. Comparisons between time points were not possible, but trends seem to indicate that patient symptoms are not being successfully managed.

PMID: 12442981 [PubMed - indexed for MEDLINE]

6: Am J Hosp Palliat Care 2002 Nov-Dec;19(6):419-25

Multidimensional continuous pain assessment chart (MCPAC) for terminal cancer patients: a preliminary report.

Bercovitch M, Waller A, Adunsky A.

Current use of pain measures is limited in clinical practice. The common pain measures neither target nor monitor the changes that occur with time with regard to the effect of other parameters associated with pain control. Changes in parameters, such as pain type, various pharmacological and nonpharmacological interventions, dosage of medications, and use of rescue doses, usually complicate pain control in terminal cancer patients. The authors propose use of a multidimensional, continuous pain chart that permits better assessment and control of pain. The chart integrates visual analogue pain assessment, special treatment techniques, regular medications and rescue doses, co-analgesics, pain categories, parameters relating to quality of life, sleep, and mobility. A total of 1,178 assessments were performed in 100 consecutive patients with full compliance. The chart permitted a continuous monitoring of patients' most important needs concerned with pain control and was easily integrated into the hospice daily routines. We conclude that the chart represents an effective and friendly graphic tool to monitor pain and associated parameters that relate to the quality of the broad spectrum of pain control. The hope is that this tool may improve pain control by hospice professionals and facilitate communication between patients and the interdisciplinary team members.

PMID: 12442980 [PubMed - indexed for MEDLINE]

7: Am J Hosp Palliat Care 2002 Nov-Dec;19(6):415-6

Conversations with the dying: tone and texture.

Gelo F.

Division of Medical Humanities, Drexel University College of Medicine,
Philadelphia, Pennsylvania, USA.

PMID: 12442978 [PubMed - indexed for MEDLINE]

8: Am J Hosp Palliat Care 2002 Nov-Dec;19(6):408-14

Comment in:

Am J Hosp Palliat Care. 2001 Mar-Apr;18(2):84.

Parallels in practice: palliative nursing practice and Parse's theory of human becoming.

Hutchings D.

Capital Health Region, Victoria, British Columbia, Canada.

Nurses experienced in the art and science of palliative nursing will find many elements of congruence between the principles and philosophy of palliative practice and the theory of human becoming. In this brief exploration of parallels in practice between Parse's theory of human becoming and traditional palliative and hospice nursing practice, the author suggests that the theory of human becoming is consistent and consonant with the values that shape palliative nursing practice. The theory is briefly described, and four parallels of practice are identified: whole person care; the presence of paradox in human experience; primacy of the person; and presence and dialogue, or "being with," dying persons. The theory of human becoming holds relevance and promise in its capacity to provide palliative and hospice nurses with a theoretical framework with which to inform and guide nursing practice with dying persons.

PMID: 12442977 [PubMed - indexed for MEDLINE]

9: Am J Respir Crit Care Med 2002 Dec 1;166(11):1430-5

Patient, physician, and family member understanding of living wills.

Upadya A, Muralidharan V, Thorevska N, Amoateng-Adjepong Y, Manthous CA.
Pulmonary and Critical Care, Bridgeport Hospital, Bridgeport, Connecticut 06610, USA.

This study examines understanding of living wills by patients, family members, and physicians. Questionnaires were used to examine whether each cohort understood patients' living wills regarding endotracheal intubation and cardiopulmonary resuscitation (CPR). Of 4,800 patients admitted during the study period, 206 reported having living wills, all of which precluded intubation and CPR for "terminal conditions." Of 140 admitted to the general hospital wards, 17 (12%) wanted their living wills to preclude intubation/mechanical ventilation and 12 (8.6%) did not want resuscitation under any circumstances. Seven of 120 (6%) physicians and 4 of 108 family members would not intubate or perform CPR even if there was a chance of recovery. Of 88 patients with complete data (including physicians and family members), 29 (33%) wanted their living wills to block intubation/mechanical ventilation only if they were deemed terminal and 46 (52%) wanted the living will to block intubation even if there was a 10% chance of recovery. Thirteen (15%) wanted to block intubation even if the chance of recovery was $\geq 50\%$. Results were similar for wishes regarding CPR. These data suggest substantial differences of patient, physician, and family member understanding of living wills. Living wills did not reflect fully patients' expectations of receiving (or not receiving) life-sustaining modalities.

PMID: 12406822 [PubMed - indexed for MEDLINE]

10: Ann Intern Med 2003 Jan 7;138(1):65-8

CPR for patients labeled DNR: the role of the limited aggressive therapy order.

Choudhry NK, Choudhry S, Singer PA.

Harvard University, Cambridge, Massachusetts, USA.

Patients who sustain a cardiac arrest have a less than 20% chance of surviving to hospital discharge. Patients may request do-not-resuscitate (DNR) orders if they believe that their chances for a meaningful recovery after cardiopulmonary arrest are low. However, in some identifiable circumstances, cardiopulmonary resuscitation (CPR) has a higher chance of success and lower likelihood of neurologic impairment. The probability of survival from a cardiac arrest influences patients' wishes regarding resuscitation; thus, when CPR has a higher likelihood of success, patients' expressed preferences for treatment as contained within a DNR order may not accurately reflect their intended goals. Patients should be offered the option of consenting to CPR for "higher-success" situations, including a witnessed cardiopulmonary arrest in which the initial cardiac rhythm is ventricular tachycardia or fibrillation, cardiac arrest in the operating room, and cardiac arrest resulting from a readily identifiable iatrogenic cause. This new level of resuscitation could be called a "limited aggressive therapy" order.

Publication Types:

Review

Review, Tutorial

PMID: 12513047 [PubMed - indexed for MEDLINE]

11: Ann Intern Med 2002 Dec 17;137(12):W2; author reply W2

Comment on:

Ann Intern Med. 2002 Jun 4;136(11):845-9.

Careful conversation about care at the end of life.

Kvasnicka JH.

Publication Types:

Comment

Letter

PMID: 12484745 [PubMed - indexed for MEDLINE]

12: Ann Intern Med 2002 Dec 17;137(12):W1; author reply W1

Comment on:

Ann Intern Med. 2002 Jun 4;136(11):845-9.

Careful conversation about care at the end of life.

Morita T, Tsuneto S, Shima Y.

Publication Types:

Comment

Letter

PMID: 12484744 [PubMed - indexed for MEDLINE]

13: Ann Intern Med 2002 Dec 17;137(12):1010-1; reply 1010-1

Comment on:

Ann Intern Med. 2002 Jun 4;136(11):845-9.

Physician involvement in voluntary stopping of eating and drinking.

Gert B, Bernat JL, Mogielnicki RP.

Publication Types:

Comment

Letter

PMID: 12484730 [PubMed - indexed for MEDLINE]

14: Ann Intern Med 2002 Dec 17;137(12):1008-10; author reply 1008-10

Comment on:

Ann Intern Med. 2002 Jun 4;136(11):845-9.

Careful conversation about care at the end of life.

Quill TE.

Publication Types:

Comment

Letter

PMID: 12484728 [PubMed - indexed for MEDLINE]

15: Ann Oncol 2002 Jun;13(6):811-2

Assisted suicide, euthanasia, mercy killing.

Publication Types:

News

PMID: 12123325 [PubMed - indexed for MEDLINE]

16: Ann R Coll Physicians Surg Can 1996 Sep;29(6):332-5

Do-not-resuscitate practice, guidelines and policies in long-term care in

Ontario: results of a survey.

Gordon M, Schwartz BE.

Baycrest Centre for Geriatric Care, 3560 Bathurst St., North York ON M6A 2E1, Canada. m.gordon@utoronto.ca

We used a survey to determine the prevalence of do-not-resuscitate (DNR) guidelines and protocols, and opinions related to cardiopulmonary resuscitation (CPR) in facilities that provide long-term care (LTC) in Ontario. Questionnaires completed by 357 of 474 facilities providing LTC, revealed that most have written DNR policies. Over half inform residents about the policy on admission, and a third later on, with most indicating DNR status on the chart. Over half the institutions can provide CPR, mostly basic cardiac life support. Most institutions rely on emergency ambulance services to treat cardiac arrests. In the absence of a DNR order, almost half will perform CPR, and a quarter have a protocol to deal with this circumstance. Most respondents indicated that staff, families and residents would welcome a protocol to deal with absent DNR orders in cardiac arrests. Most believe that staff, families and residents would welcome DNR as the basic policy, with CPR as the exception. There is a high awareness in facilities that provide LTC of the limits of CPR in the elderly. Without specific legislation, most facilities have policies and protocols, but there are inconsistencies across Ontario.

PMID: 12378754 [PubMed - indexed for MEDLINE]

17: Annu Rev Med 2003;54:53-72

Update in palliative medicine and end-of-life care.

Abraham JL.

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Palliative medicine includes clinical palliative care, education, and research that focus on the quality of life of patients with advanced disease and their families. The domain of palliative medicine is the relief of suffering: physical, psychological, social, and spiritual. Palliative medicine and care for patients at the end of life and their families include the following key components: compassionate communication; exploration of patient and family values and goals of care; expert attention to relief of suffering; management of pain, depression, delirium, and other symptoms; awareness of the manifestations of grief; and sensitivity to the concerns of bereaved survivors.

PMID: 12525669 [PubMed - in process]

18: BMJ 2002 Dec 7;325(7376):1326

Withholding the artificial administration of fluids and food from elderly patients with dementia: ethnographic study.

The AM, Pasman R, Onwuteaka-Philipsen B, Ribbe M, van der Wal G.

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OBJECTIVE: To clarify the practice of withholding the artificial administration of fluids and food from elderly patients with dementia in nursing homes. DESIGN: Qualitative, ethnographic study in two phases. SETTING: 10 wards in two nursing homes in the Netherlands. PARTICIPANTS: 35 patients with dementia, eight doctors, 43 nurses, and 32 families. RESULTS: The clinical course of dementia was considered normal and was rarely reason to begin the artificial administration of fluids and food in advanced disease. Fluids and food seemed to be given mainly when there was an acute illness or a condition that needed medical treatment and which required hydration to be effective. The medical condition of the patient, the wishes of the family, and the interpretations of the patients' quality of life by their care providers were considered more

important than living wills and policy agreements. CONCLUSIONS: Doctors' decisions about withholding the artificial administration of fluids and food from elderly patients with dementia are influenced more by the clinical course of the illness, the presumed quality of life of the patient, and the patient's medical condition than they are by advanced planning of care. In an attempt to understand the wishes of the patient doctors try to create the broadest possible basis for the decision making process and its outcome, mainly by involving the family.

Publication Types:

Multicenter Study

PMID: 12468479 [PubMed - indexed for MEDLINE]

19: BMJ 2002 Dec 7;325(7376):1320

Woman who had attended euthanasia workshop kills herself.

Zinn C.

Publication Types:

News

PMID: 12468467 [PubMed - indexed for MEDLINE]

20: Can Psychol 2000 Aug;41(3):174-83

The role of the psychologist in determining competence for assisted suicide/euthanasia in the terminally ill.

Galbraith KM, Dobson KS.

University of Calgary, Canada.

This paper discusses the history of assisted suicide/euthanasia and public attitudes in Canada; discusses depression in the terminally ill and the potential role of the psychologist in the assisted suicide/euthanasia process; and specifically addresses the importance of determining competence in terminally ill patients. One area in which the services of psychologists have not been used to their fullest potential is in the care of the terminally ill, particularly in helping them make end-of-life decisions. It is very important that individuals making end-of-life decisions be used to assessed for mental disorders in order to ensure that they are able to make competent decisions. If

assisted suicide and euthanasia were to become legalized, psychologists should be involved in the assessment process in order to determine competency.
PMID: 12484401 [PubMed - indexed for MEDLINE]

21: Cancer Invest 2002;20(7-8):1086-104

Use of family proxies in quality of life research for cancer patients at the end of life: a literature review.

Tang ST, McCorkle R.

National Yang-Ming University, College of Nursing, College of Nursing, 155 Li-Nong St, Sec 2, Peitou, Taipei, Taiwan, ROC.

One of the main goals of end-of-life care is to achieve the best quality of life (QOL) for patients and their families. Quality of life, therefore, represents a significant outcome indicator to evaluate end-of-life care interventions. However, nonresponse bias and nonrandom missing data in QOL research at the end-of-life limits the generalizability and threatens the internal validity of the study findings. The use of family proxy of patients' QOL has been suggested as a solution. Demonstration of satisfactory levels of agreement between proxies and patients is warranted before family caregivers' or other proxies' assessments can be employed when patients cannot provide their own information. Contrary to the conclusion made by Sprangers and Aaronson [The Role of Health Care Providers and Significant Others in Evaluating the Quality of Life of Patients with Chronic Disease: A Review. J. Clin. Epidemiol. 1992, 45, 743-760], it is suggested from this review of literature that terminal cancer patients and their family caregivers agreed at least moderately well on the patients' QOL. The bias introduced by the use of family informants is generally of a modest magnitude. When discrepancies existed, without exception, family caregivers held a more negative view of patients' QOL than did patients. When using family proxies, this is important to remember. The degree of agreement between terminal cancer patients' and their family caregivers' assessments varies as a function of the dimensions of QOL being measured and the patient's health status. However, the accuracy of family caregivers' assessments can be improved by assessing both patients and family caregivers concurrently over time. Several suggestions for future research are provided to better understand the influencing factors of agreement between patients and family assessments and to enhance the quality of statistical analyses on this topic.

Publication Types:

Review

Review Literature

PMID: 12449742 [PubMed - indexed for MEDLINE]

22: Cancer Nurs 2002 Dec;25(6):486-92

Solving family-related barriers to truthfulness in cases of terminal cancer in Taiwan. A professional perspective.

Hu WY, Chiu TY, Chuang RB, Chen CY.

Department of Nursing Science, College of Medicine and Hospital, National Taiwan University. weyuhu@ha.mc.ntu.edu.tw

The study investigated the puzzling factors and solutions of family-related barriers to truthfulness with patients with terminal cancer through a nationwide survey conducted in Taiwan. Two-hundred twenty-nine valid questionnaires were retrieved (91.6%) from 250 palliative care workers at 15 Taiwan hospices. Most of the respondents were nursing staff (72.5%), and only 38 respondents were physicians (16.6%). Canonical correlation analysis was used to examine the

association between the puzzling factors and solutions, which revealed that the value of the first variate was 0.39 ($P < .05$). Results showed that the puzzling factors of barriers and canonical loadings were families do not know how to tell the truth (.85), families believe it is unnecessary to tell aged patients the truth (.71), and patients can be happier without knowing the truth (.70). The valid solutions correlated significantly with the above puzzling factors and were ranked in the following order: communicate with and encourage families to accept patients' prognoses (.83), discuss the sickness gently with patients and determine what patients know (.76), and tell the families about the possible emotional reactions in patients and how to provide support (.72). In conclusion, for solving family-related barriers to truthfulness in cases of terminal cancer, the results suggest that health professionals communicate with families first and discuss the possible emotional reactions from patients, give patients enough time to reflect on their sicknesses and discuss further what patients have been told, and then disclose information based on patients' expectations and support them.

PMID: 12464841 [PubMed - indexed for MEDLINE]

23: Chest 2003 Jan;123(1):16-8

End-of-Life Care and Eudaemonia.

Fromm GB.

Dr. Fromm is a Pulmonary-Critical Care private practitioner at Memorial Hospital.

PMID: 12527596 [PubMed - in process]

24: Chest 2003 Jan;123(1 Suppl):312S-331S

End-of-Life Care in Patients With Lung Cancer.

Griffin JP, Nelson JE, Koch KA, Niell HB, Ackerman TF, Thompson M, Cole FH Jr.

From the Division of Pulmonary and Critical Care Medicine (Drs. Griffin and Thompson), Division of Hematology/Oncology (Dr. Niell), Department of Medicine, the Department of Human Values and Ethics (Dr. Ackerman), the Section of Thoracic and Cardiovascular Surgery (Dr. Cole), Department of Surgery, College of Medicine, The University of Tennessee Health Science Center, Memphis, TN.

Evidence-based practice guidelines for end-of-life care for patients with lung cancer have been previously available only from the British health-care system. Currently in this setting, there has been increasing concern in attaining control of the physical, psychological, social, and spiritual distress of the patient and family. This American College of Chest Physicians'-sponsored multidisciplinary panel has generated recommendations for improving quality of life after examining the English-language literature for answers to some of the most important questions in end-of-life care. Communication between the doctor, patient, and family is central to the active total care of patients with disease that is not responsive to curative treatment. The advance care directive, which has been slowly evolving and is presently limited in application and often circumstantially ineffective, better protects patient autonomy. The problem-solving capability of the hospital ethics committee has been poorly utilized, often due to a lack of understanding of its composition and function. Cost considerations and a sense of futility have confused caregivers as to the potentially important role of the critical care specialist in this scenario. Symptomatic and supportive care provided in a timely and consistent fashion in the hospice environment, which treats the patient and family at home, has been increasingly used, and at this time is the best model for end-of-life care in the United States.

PMID: 12527587 [PubMed - as supplied by publisher]

25: Chest 2003 Jan;123(1):266-71

Impact of a Proactive Approach to Improve End-of-Life Care in a Medical ICU.
Campbell ML, Guzman JA.

Palliative Care Service, Detroit Receiving Hospital, and the Division of Pulmonary and Critical Care Medicine, Wayne State University, Detroit, MI.
STUDY OBJECTIVE:s: To assess the impact of a proactive case finding approach to end-of-life care for critically ill patients experiencing global cerebral ischemia (GCI) after cardiopulmonary resuscitation and multiple organ system failure (MOSF) in comparison to historical control subjects. DESIGN: Comparative study of retrospective and prospective cohorts. SETTING: Medical ICU of a university hospital. INTERVENTIONS: Patterns of end-of life care for patients with MOSF and GCI obtained through a retrospective chart review were compared to proactive case finding facilitated by the inpatient palliative care service. Interventions included identification of patient's advance directives or preferences about end-of life care, if any; assistance with discussion of the prognosis and treatment options with patients or their surrogates; and implementation of palliative care strategies when treatment goals changed to a focus on comfort measures. RESULTS: Although our retrospective data demonstrated a high percentage of do-not-resuscitate decisions for the patients under investigation, a considerable time lag elapsed between identification of the poor prognosis and the establishment of end-of-life treatment goals (4.7 +/- 2.4 days and 3.5 +/- 0.5 days for patients with MOSF and GCI, respectively [mean +/- SE]). The proactive case finding approach decreased hospital length of stay (mean, 20.6 +/- 4.1 days vs 15.1 +/- 2.5 days and 8.6 +/- 1.6 days vs 4.7 +/- 0.6 days for MOSF and GCI patients, respectively; p = 0.063 and < 0.001, respectively). More importantly, a proactive palliative care intervention decreased the time between identification of the poor prognosis and the establishment of comfort care goals (7.3 +/- 2.9 days vs 2.2 +/- 0.8 days and 6.3 +/- 1.2 days vs 3.5 +/- 0.4 days for MOSF and GCI patients, respectively; p < 0.05 for both), decreased the time dying patients with MOSF remained in the ICU, and reduced the use of nonbeneficial resources, thus reducing the cost of care. CONCLUSIONS: Proactive interventions from a palliative care consultant within this subset of patients decreased the use of nonbeneficial resources and avoided protracted dying.

PMID: 12527629 [PubMed - in process]

26: Chest 2002 Nov;122(5):1867-8; author reply 1868

Comment on:

Chest. 2002 Mar;121(3):957-63.

End-of-life care: data supportive?

Arnett J Jr.

Publication Types:

Comment

Letter

PMID: 12426300 [PubMed - indexed for MEDLINE]

27: Clin Nurse Spec 2002 Nov;16(6):293-4

How are you facilitating advance directives in your clinical nurse specialist practice?

Calvin AO, Clark AP.

The University of Texas Health Science Center at Houston, USA.

PMID: 12464843 [PubMed - indexed for MEDLINE]

28: Comp Int Law J South Afr 2000 Jul;33(2):193-209

Decision-making at the end of life: the termination of life-prolonging treatment, euthanasia (mercy-killing) and assisted suicide in Canada in South Africa.

Sneiderman B, McQuoid-Mason D.

University of Manitoba, Canada.

PMID: 12425314 [PubMed - indexed for MEDLINE]

29: Conn Med 2002 Nov;66(11):655-64

How can we improve care at the end of life in Connecticut? Recommendations from focus groups.

McGraw SA, Dobihal E, Baggish R, Bradley EH.

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A qualitative study to elicit views among residents of Connecticut about death, dying, preferences for care, and gaps in available care was conducted for the Connecticut Coalition to Improve End-of-Life Care. Twenty-eight focus groups were convened across the state between May 1999 and March 2001. The focus groups

included adolescents and adults from diverse religious, ethnic, and professional backgrounds. A total of 196 individuals participated in the 90-minute sessions.

Trained moderators conducted the discussion groups following a guide.

Transcriptions of the groups were coded to identify themes. Thirty-two recommendations to improve care based on the focus group discussions are presented. These are grouped under the following actions: 1) enhance public education; 2) offer better professional provider education and support; and 3) augment services. The recommendations are illustrated with quotations from the focus groups.

PMID: 12476507 [PubMed - indexed for MEDLINE]

30: Conn Med 2002 Nov;66(11):649-54

How we die in America--our crisis in American health caring.

Duffy J.

Department of Psychiatry, University of Connecticut School of Medicine, Farmington, USA.

PMID: 12476506 [PubMed - indexed for MEDLINE]

31: Conn Med 2002 Nov;66(11):665-9

Dying in Connecticut--the facts.

McGloin JM.

Program on Aging, Yale University School of Medicine, New Haven, Connecticut, USA.

PMID: 12476508 [PubMed - indexed for MEDLINE]

32: Conn Med 2002 Nov;66(11):671-5

Best practices in hospital end-of-life care.

Coll PP, Duffy JD, Micholovich E, Cohen S.

University of Connecticut Health Center, Center on Aging, Farmington, Qualidigm, Middletown, USA.

The Connecticut Best Practices in End-of-Life Care project was initiated in response to the concern that Connecticut hospitals were not meeting the needs of dying patients. The records of 420 patients with a diagnosis of cancer or with an admission to an intensive-care unit were reviewed for the period 04/01/2000 to 03/31/2001. Utilizing a chart extraction tool, measures of "best practice" were developed as a means of assessing the quality of end-of-life care provided

to the patient cohort. Some of the findings on the "best practice" indicators were as follows: 65 (15.3%) of the patient cohort died during their hospital stay. Three hundred forty (81.3%) had a pain assessment on admission. Three hundred eighty-six (92.6%) had a pain assessment on at least one occasion during their hospital stay. Two hundred forty-two of 397 (61%) patients who received an analgesic medication had their pain reassessed within four hours of receiving the medication. One hundred ninety-five (46.4%) patients had their prognosis discussed with them. Eighteen patients (< 5%) were referred to hospice. Connecticut hospitals are doing well in assessing patient pain. However, they are doing poorly in discussing prognosis with sick patients and referring them to hospice.
PMID: 12476509 [PubMed - indexed for MEDLINE]

33: Conn Med 2002 Nov;66(11):677-81
Should we focus more on the individual? A discussion of current advance-care planning law in Connecticut.
McEvoy K.
PMID: 12476510 [PubMed - indexed for MEDLINE]

34: Conn Med 2002 Nov;66(11):691-6
Perspectives on preparedness for a death among bereaved persons.
Barry LC, Prigerson HG.
Department of Epidemiology and Public Health, Yale University School of Medicine, USA.
OBJECTIVE: To present opinions of recently bereaved persons regarding how they could have been made to feel more prepared for the death of a loved one.
METHODS: Cross-sectional descriptive study that uses information from a longitudinal study. A face-to-face interview was administered to 122 recently bereaved persons and participants were asked to provide opinions and to describe whether health professionals, family/friends, or themselves could have helped them to feel more prepared for the death. RESULTS: Of the total sample of 122, 31 (25%) reported that doctors or health professionals could have done something more to help make them feel better prepared for the death of their loved-one. Six subjects (4.9%) indicated family/friends, and 16 (13.1%) stated that they themselves could have done something more to help prepare for the death of their loved-one. Common themes were: the physicians' lack of communication regarding the prognosis and imminence of death, family survivors' concerns about the medical care provided, regrets engendered by their own denial of the patient's imminent death, not managing the illness in a manner consistent with the patient's impending death, and lost opportunities for closure in family matters, both financial and interpersonal. DISCUSSION: Findings from this study can be used to enhance understanding of bereaved persons' views about health professionals' current practices for bereaved individuals, as well as the role of the family and the bereaved persons themselves in potentially effecting preparedness for the death of a loved one.
PMID: 12476512 [PubMed - indexed for MEDLINE]

35: Conn Med 2002 Nov;66(11):699-702
Physician-assisted suicide and palliative care: beliefs and empiricism in the policy debate.
Schwartz HI, Curry L.
University of Connecticut School of Medicine.
This article provides a brief overview of recent research on the practice of

physician-assisted suicide (PAS) in Connecticut. In addition, the article examines recent empirical evidence about the role of depression in patients' end-of-life decisions, and synthesizes relevant literature on the relationship between PAS and palliative care in the context of recent experience in Oregon.
Publication Types:

Review

Review, Tutorial

PMID: 12476513 [PubMed - indexed for MEDLINE]

36: Curr Opin Oncol 2002 Jul;14(4):394-8

Dyspnea: the continuing challenge of palliative management.

LeGrand SB.

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The management of dyspnea is a challenge even for the most experienced palliative medicine teams. In the absence of effective treatment for the underlying disease, therapeutic options are limited to the supplementation of oxygen, the use of opioids, and multidisciplinary nonpharmacologic interventions. There is increased research into both the physiology of dyspnea and the correlates of the symptom in advanced disease. Hopefully, this research will lead to improved therapy in the future. This article reviews current literature on dyspnea with a focus on publications in 2001.

Publication Types:

Review

Review, Tutorial

PMID: 12130922 [PubMed - indexed for MEDLINE]

37: Geriatr Nurs 2002 Nov-Dec;23(6):296-301

Long-term care nurses' knowledge of end-of-life care.

Raudonis BM, Kyba FC, Kinsey TA.

BARBARA M. RAUDONIS, PhD, RN, CS, is an assistant professor, FERNE C.N. KYBA, PhD, RN, is a clinical professor and director of the RN-BSN program, and TERRI A. KINSEY, RN, MSN, LCDR, NC, SWMDO, USN, was a graduate student at the University of Texas at Arlington School of Nursing.

Long-term care (LTC) facilities usually contract with hospice agencies to provide palliative (comfort) care to their terminally ill residents, yet only 1% of nursing home residents enroll in hospice care. Integrating hospice services with nursing home services presents many challenges. One of the most critical challenges is the lack of education in palliative care among physicians, licensed nurses, and certified nursing assistants in LTC settings. A study of 164 licensed nurses from 24 LTC facilities in north central Texas found deficiencies in their knowledge of palliative care. The mean score on the Palliative Care Quiz for Nursing was 12.3 of a possible 20 (62%, SD = 2.7). Implications for practice include a critical need for in-service education on end-of-life content for practicing LTC nurses and integration of such content in all curricula for future nurses.

PMID: 12494000 [PubMed - as supplied by publisher]

38: Harv J Law Public Policy 2000 Spring;23(2):599-710

The right to assisted suicide and euthanasia.

Gorsuch NM.

Kellogg, Huber, Hansen, Todd & Evans, P.L.L.C.

Publication Types:

Review

Review, Academic

PMID: 12524693 [PubMed - indexed for MEDLINE]

39: Harv J Law Public Policy 2000 Spring;23(2):487-550
Death, ethics and the state.

Kalt BC.

Sidley & Austin, Washington, DC, USA.

PMID: 12452157 [PubMed - indexed for MEDLINE]

40: Health Care Financ Rev 2001 Fall;23(1):137-47

Including hospice in Medicare capitation payments: would it save money?

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Hospice services received by Medicare risk-based health maintenance organization (HMO) enrollees are paid on a non-capitated basis, creating financial incentives for HMOs to encourage their terminally ill patients to elect hospice. Using Medicare administrative records for 1998, we found that hospice enrollment in the last month of life was significantly higher among HMO enrollees than among beneficiaries in fee-for-service (FFS). However, low mortality rates among HMO enrollees produced similar population-based rates of hospice use in the HMO and FFS sectors. Simulations showed that including hospice care under capitation payments in July 1998 would have produced very small savings for Medicare.

PMID: 12500368 [PubMed - indexed for MEDLINE]

41: Health Care Food Nutr Focus 2002 Nov;19(3):6-7

Nutrition and hospice.

Dahl M.

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PMID: 12404991 [PubMed - indexed for MEDLINE]

42: Health Policy 2002 Nov;62(2):161-72

Future health care costs--do health care costs during the last year of life matter?

Madsen J, Serup-Hansen N, Kristiansen IS.

Institute of Public Health, Health Economics and Aging Research Center, 19 Winslow Park, University of Southern Denmark, DK-5000 C Odense, Denmark. While some studies have shown a considerable effect of ageing upon future health care costs, others indicate small or no effects. Moreover, studies have shown that age-related increases in health care costs in part can be explained by high costs in the last year of life. The aim of this study was to project future costs of hospital in-patient care and primary health care services in Denmark on the basis of demographic changes, both with and without account for the high costs in the last year of life. Costs were projected on the basis of a random 19% sample of the Danish population using the cohort-component method. The traditional projection method does not account for the high costs in the last year of life while the 'improved' method does. The Danish population was projected to increase by 8.2% during the period 1995-2020, and health care costs by 18.5% according to the traditional projection method and 15.1% according to the improved one. These results suggest that the high costs in the last year of life does matter in projections of future health care costs and should be taken into account. Furthermore, ageing per se seems to have considerable impact on future health care costs.

PMID: 12354410 [PubMed - indexed for MEDLINE]

43: Home Healthc Nurse 2002 Nov;20(11):748-50

Contracted facility-based hospice care: the Joint Commission survey process.
Friedman MM.
mmf@mindspring.com
PMID: 12442046 [PubMed - indexed for MEDLINE]

44: Hosp Top 2002 Summer;80(3):25-9

Hospital executive leadership: a critical component for improving care at the end of life.

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End-of-life care and its planning by individuals, in concert with their families and professional healthcare givers, pose important social, legal, and ethical issues. The authors evaluate the results of a multi-year (1997-2001) collaborative effort among representatives of Georgia healthcare providers, healthcare payers, and the general public that was designed to (a) improve end-of-life care through a community-focused field effort to increase public awareness, execution, and institutional management of advance directives and (b) impact institutional and state government systems and policies around end-of-life care. The authors conclude that a proactive presence of senior management is integral in implementing systematic change in hospital-based end-of-life care and offer practical recommendations to hospital leaders to affect real change in their institutions.

PMID: 12471882 [PubMed - indexed for MEDLINE]

45: ILSA J Int Law 1998 Spring;4(2):817-34

The right to die with dignity with the assistance of a physician: an Anglo, American and Australian international perspective.

Woods E.

PMID: 12236256 [PubMed - indexed for MEDLINE]

46: Int Urol Nephrol 2002;33(1):139-44

Staff-assisted home hemodialysis in debilitated or terminally ill patients.

Agraharkar M, Barclay C, Agraharkar A.

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End stage renal disease (ESRD) patients who are diagnosed to have a terminal illness or severe debility have limited options for their continued care. This results in a frequent decision to withdraw dialysis support. Due to their tenuous condition, continued transportation to the dialysis facility further aggravates the emotional, financial and physical burden to the patient and family. We would like to present our data on 28 patients with severe debilitating and terminal illnesses. The mean age was 69 years with a (+/-) 11.8 SD and range of 44-87 years. Nine of them were males and 19 females. All of these were considered terminally ill as most of these patients had multi-organ failure. Ten had stroke, 16 had cardiac failure, 2 had severe vascular insufficiency, one resulting in bilateral leg amputation, 5 had debilitating pulmonary disease needing oxygen therapy and 8 had cancer. These patients were dialyzed at their home by a registered nurse (RN) according to a dialysis prescription provided by an attending nephrologist. Twenty-three patients died at home, one transferred to acute care facility and 3 to hospice care after a mean staff-assisted home hemodialysis (SAHD) duration of 14.1+/-2.9 weeks. ESRD patients with severe disability can continue dialysis in a more convenient and comfortable setting at home, and yet be relatively cost-effective.

PMID: 12090321 [PubMed - indexed for MEDLINE]

47: Intensive Care Med 2002 Sep;28(9):1197-9

Comment on:

Intensive Care Med. 2002 Sep;28(9):1309-15.

Excellence in end-of-life care: a goal for intensivists.

Troung RD, Burns JP.

Publication Types:

Comment

Editorial

PMID: 12400561 [PubMed - indexed for MEDLINE]

48: Intensive Care Med 2002 Sep;28(9):1309-15

Comment in:

Intensive Care Med. 2002 Sep;28(9):1197-9.

A four-step protocol for limitation of treatment in terminal care. An observational study in 475 intensive care unit patients.

Holzapfel L, Demingeon G, Piralla B, Biot L, Nallet B.

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OBJECTIVE: To describe a four-step protocol for withholding and withdrawal of life support (WH/WDLS) in intensive care unit (ICU) terminal patients. DESIGN: Observational study. SETTING: A 10-bed ICU of a general hospital. PATIENTS: Eighty-three patients out of 475 consecutive patients admitted over a 1 year period had WH/WDLS. INTERVENTIONS: The healthcare team chose a pattern of treatment limitation on a four-step protocol for every patient every day. There were four alternatives: group 1: no limitation of care; group 2: patient designated do not resuscitate (DNR) and pressors limited to dopamine at a maximum dose of 20 microg/kg per min; others therapies were continued; group 3: active withdrawal of all therapy except comfort care, i.e., the patient continued to receive nursing, sedation/analgesia, hydration and mechanical ventilation with FIO2=0.21 and no positive end-expiratory pressure (PEEP). Sedation was adjusted to Ramsay 3-4. The group 4 was treated the same as group 3 except that minute ventilation was 5 l/min and sedation/analgesia adjusted to Ramsay 6. WH/WDLS was performed only if the full ICU staff and all family members agreed with the procedure. WH/WDLS was documented in the patient's chart. RESULTS: Withholding and withdrawal of life support was performed in 83 patients (17%): 25 patients in group 2 (15 deaths), 36 patients in group 3 (36 deaths) and 22 patients in group 4 (22 deaths). Finally, 73 patients died after WH/WDLS. ICU stay was 10+/-17 days, time from admission to WH/WDLS was 184+407 h

and time from WH/WDLS to death was 64+/-84 h. CONCLUSION: This four-step protocol may promote medical decision making on end-of-life care.

PMID: 12209282 [PubMed - indexed for MEDLINE]

49: J Am Acad Nurse Pract 2002 Nov;14(11):517-22

End-of-life treatment preferences among older adults: a nurse practitioner initiated intervention.

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PURPOSE: To explore end-of-life treatment preferences (ELTP) among older adults and to test the impact of a nurse practitioner (NP) initiated intervention to facilitate the completion of ELTPs. DATA SOURCES: A descriptive study including 135 older adults living in a continuing care retirement community. CONCLUSIONS:

The findings in this study suggest that the majority of older adults do not want life sustaining interventions at the end of life, but are willing to accept interventions that will keep them comfortable. ELTP can, however, change over time. An NP-initiated teaching intervention about advance directives and ELTP significantly increased the number of individuals who completed advance directive forms. IMPLICATIONS FOR PRACTICE: With the advancement of medical technology, various life-sustaining treatments are available at the end of life. Older adults should be encouraged to establish their ELTPs while they are physically and mentally able to do so. Health care providers should initiate discussions about ELTP at regular intervals (yearly) to assist older adults in participating in decisions about their end-of-life care.
PMID: 12479154 [PubMed - indexed for MEDLINE]

50: J Clin Nurs 2002 Nov;11(6):794-801

Management of relatives of patients who are dying.

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Previous research in a retrospective community-based study suggested that some relatives had difficulty coping with their bereavement when the pre-bereavement period had not been managed well. This prospective study in a hospital setting explored the issues further to include the views and needs of staff as well as relatives. Staff were interviewed in focus groups and relatives were interviewed individually. Analysis of data was qualitative using thematic analysis. Findings demonstrated that staff often felt ill-equipped for providing support for relatives when a patient is dying. Training is required to help nurses support and care for the relatives of dying patients.

PMID: 12427185 [PubMed - indexed for MEDLINE]

51: J Clin Oncol 2002 Dec 15;20(24):4699-704

Attitudes of Japanese physicians toward terminal dehydration: a nationwide survey.

Morita T, Shima Y, Adachi I; Japan Palliative Oncology Study Group.

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PURPOSE: To clarify physician attitudes toward terminal dehydration and identify the physician-related factors contributing to their attitudes. METHODS: A cross-sectional survey of Japanese physicians with a self-reported questionnaire was used. RESULTS: A total of 584 responses were analyzed (response rate, 53%). In the vignette of a gastric cancer patient with an estimated survival of 1 month and almost impossible oral intake due to intestinal obstruction, 50% chose intravenous hydration of 1,000 mL/d, while 24% selected more than 1,500 mL/d. For a lung cancer patient with cachexia, 58% chose 1,000 mL/d, while 26% selected no hydration or 500 mL. Multivariate analyses revealed that the physicians with more positive attitudes toward intravenous hydration were significantly less involved in end-of-life care, more likely to regard the physiologic requirement of fluid and nutrition as important in initiating intravenous hydration, more likely to believe that intravenous hydration is effective for symptom palliation, and more likely to believe that intravenous hydration is the minimum standard of care. CONCLUSION: Physicians have considerably divergent attitudes toward intravenous hydration for terminally ill cancer patients. To resolve the discrepancy, the priority in hydration research should be to clarify the appropriate physiologic requirements of fluid and nutrition in dying patients, the effects of intravenous hydration on patient symptoms, and the reasons why physicians consider intravenous hydration to be

the minimum standard of care.

PMID: 12488416 [PubMed - indexed for MEDLINE]

52: J Contin Educ Nurs 2002 Nov-Dec;33(6):270-8

Teaching cultural considerations at the end of life: end of life nursing education consortium program recommendations.

Matzo ML, Sherman DW, Mazanec P, Barber MA, Virani R, McLaughlin MM. New Hampshire Community Technical College, Manchester, USA.

BACKGROUND: The End of Life Nursing Education Consortium (ELNEC) is an end of life care nursing education program that addresses the many dimensions of culture, including ethnic identity, gender, age, differing abilities, sexual orientation, and religion and spirituality. This article focuses on one of the program's modules entitled "Cultural Considerations in End of Life Care."

METHOD: The ELNEC "Cultural Considerations in End of Life Care" module, which identifies important cultural considerations as well as strategies and responses to teach cultural competence and sensitivity in undergraduate nursing curriculum, is described. FINDINGS: A total of 564 nursing faculty members and 707 continuing education faculty members have undergone ELNEC training.

Essential module components including teaching strategies and resources are presented. CONCLUSION: Comprehensive education for nurses regarding cultural considerations in end of life care results in improved care for dying patients who ultimately have a peaceful, respectful death with sensitivity to their cultural expectations and needs.

PMID: 12442876 [PubMed - indexed for MEDLINE]

53: J Contin Educ Nurs 2002 Nov-Dec;33(6):279-82

Design of a postgraduate course in palliative care.

Adriaansen MJ, Frederiks C.

Department of Nursing, Hogeschool van Arnhem en Nijmegen, The Netherlands.

BACKGROUND: Although palliative care is multidisciplinary in nature, nurses play an essential role in terminal care. Because new nurses frequently lack the specific skills for palliative nursing care as well as competence in interdisciplinary practice, there is a need for continuing education in palliative care. This article describes a postgraduate course in palliative care for nurses.

METHOD: A postgraduate course was developed based on the needs of palliative patients and the subjective and objective needs of nurses. FINDINGS: Four roles assumed by nurses in palliative care were identified: bureaucratic, biomedical, social-therapeutic, and informal. The actual results of the course were influenced by the contextual aspects, which were determined by the nursing environment. Assignments were formulated according to the needs of the nursing unit, and a number of peer review meetings were organized.

CONCLUSION: Successful implementation of a postgraduate course in palliative care increases nurses' expertise and offers an opportunity for nurses to exchange experiences and search for solutions to problems together.

PMID: 12442877 [PubMed - indexed for MEDLINE]

54: J Crim Law Criminol 1998 Spring;88(3):1155-65

Comment on:

J Crim Law Criminol. 1998 Spring;88(3):1121-46.

Physician assisted suicide and voluntary euthanasia: some relevant differences.

Deigh J.

Northwestern University, USA.

Publication Types:

Comment

PMID: 12455525 [PubMed - indexed for MEDLINE]

55: J Med Ethics 2002 Oct;28(5):303-7

Increasing use of DNR orders in the elderly worldwide: whose choice is it?

Cherniack EP.

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Most elderly patients die with an order in place that they not be given cardiopulmonary resuscitation (DNR order). Surveys have shown that many elderly in different parts of the world want to be resuscitated, but may lack knowledge about the specifics of cardiopulmonary resuscitation (CPR). Data from countries other than the US is limited, but differences in physician and patient opinions by nationality regarding CPR do exist. Physicians' own preferences for CPR may predominate in the DNR decision making process for their patients, and many physicians may not want the participation of the elderly or believe that it is necessary. More complete and earlier discussions of a wider range of options of care for patients at the end of life have been advocated. The process ought to include education for patients about the process and efficacy of CPR, and for physicians on how to consider the values and levels of knowledge of their patients, whose preferences may differ from their own.

Publication Types:

Review

Review, Tutorial

PMID: 12356958 [PubMed - indexed for MEDLINE]

56: J Med Pract Manage 2002 Sep-Oct;18(2):101-3

Withdrawing life-sustaining treatment from minimally conscious patients: who decides?

Anderson BJ.

Anderson_3871@msn.com

PMID: 12389332 [PubMed - indexed for MEDLINE]

57: J Nurs Scholarsh 2000;32(3):222

Comment on:

Image J Nurs Sch. 1999;31(4):367-73.

On assisted dying.

Freeman KA.

Publication Types:

Comment

Letter

PMID: 12462812 [PubMed - indexed for MEDLINE]

58: J Pain Symptom Manage 2002 Sep;24(3):291-8

Hospital care at the end of life: an institutional assessment.

Jacobs LG, Bonuck K, Burton W, Mulvihill M.

Department of Medicine, Division of Geriatrics, Albert Einstein College of
Medicine and Montefiore Medical Center, Bronx, NY, USA.

Decisions about care at the end of life are not only influenced by doctor-patient-family relationships and physician practice, but also by institutional "culture." An institutional assessment of the quality of care provided to dying hospitalized patients was undertaken to characterize and identify factors influencing it and to find opportunities for improvement. An analysis of hospital data, three physician and nursing focus group discussions, structured review of records of targeted patients (61) who had an "expected death," and interviews with 31 surviving family members of the targeted patients served as the basis for an institutional needs assessment intended to precede the development of a quality improvement program to improve hospital care of

patients at the end of life. Data were primarily gathered regarding older adults, including a significant number of nursing home residents. The assessment led to a methodology for developing a quality improvement program based upon feedback to physicians and nurses regarding the quality of end-of-life care.
PMID: 12458110 [PubMed - indexed for MEDLINE]

59: J Pain Symptom Manage 2002 Sep;24(3):299-311
Can "Palliative Care Reports" improve end-of-life care for hospitalized patients?

Jacobs LG, Bonuck K, Burton W.

Department of Medicine, Division of Geriatrics, Montefiore Medical Center and Albert Einstein College of Medicine, Bronx, NY 10467, USA.

Improvement in the care of dying hospitalized patients was sought by providing evaluative feedback to individual physicians (n = 46) and nurses in three biannual "Palliative Care Reports." Hospitalized adult patients (n = 194) for whom "death was probable" were prospectively identified from the critical care or geriatric services, and a "palliative care" social work evaluation provided. Educational sessions on palliative care were held for physicians and nurses. Medical record review and family interviews were used to generate 10 scores per patient, which evaluated satisfaction with care, relief of symptoms (pain, dyspnea, gastrointestinal, psychological), and the timeliness of care planning. Subjective comments from a quality improvement committee and focussed educational material was also included. Despite these efforts, no change in the cohort's median report scores occurred over the 18 months, but several institutional policies were examined and altered, and interest and support for a palliative care consultation service was obtained.

PMID: 12458111 [PubMed - indexed for MEDLINE]

60: J Pain Symptom Manage 2002 Sep;24(3):328-34
A retrospective observation of corticosteroid use at the end of life in a hospice.

Gannon C, McNamara P.

Princess Alice Hospice, Surrey, United Kingdom.

This study aimed to clarify corticosteroid prescribing during final hospice care, realizing the clinical and ethical dilemmas that may be associated with this therapy. A retrospective review was performed of deaths occurring at our unit during a 6-month period. Corticosteroid use was recorded from drug charts and cross-referenced by case note review. Fifty-one percent of 178 patients received corticosteroids, which were continued until death in 53%. Only 2% were switched from oral to parenteral corticosteroids. The reason for using corticosteroids was documented in 67% of patients. The main indications included treatment for raised intracranial pressure and to give a "boost." The foremost reason for withdrawing corticosteroids was loss of the oral route. These data confirm the high prevalence of corticosteroid use in the terminal phase, even until death. This contrasted with the near absolute withdrawal of corticosteroids once the oral route was lost. The study suggests a need for greater vigilance in corticosteroid prescribing, and identified issues to be addressed in the prescribing of these drugs.

PMID: 12458114 [PubMed - indexed for MEDLINE]

61: J Pain Symptom Manage 2002 Sep;24(3):312-7
Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington.

Ganzini L, Silveira MJ, Johnston WS.

Mental Health Division, Oregon Health and Science University, Portland, USA.

To understand the factors associated with interest in assisted suicide among terminally ill patients, we surveyed 50 caregivers of decedent amyotrophic lateral sclerosis (ALS) patients from Oregon and Washington regarding perceptions of patients' interest in assisted suicide and their physical and emotional state in the last month of life. For 38 caregivers, we had baseline information from the patients themselves, gathered a median of 11 months before death, regarding depression, hopelessness, sense of burden, social support, quality of life, pain, and suffering. According to our respondents, one-third of ALS patients discussed wanting assisted suicide in the last month of life. Hopelessness and interest in assisted suicide at baseline predicted desire for assisted suicide later on. ALS patients who were interested in assisted suicide, compared to those who were not, had greater distress at being a burden to others and more insomnia, pain, and discomfort other than pain.
PMID: 12458112 [PubMed - indexed for MEDLINE]

62: J Palliat Med 2002 Aug;5(4):487-96

End-of-life care education in internal medicine residency programs: an interinstitutional study.

Mullan PB, Weissman DE, Ambuel B, von Gunten C.
Michigan State University, East Lansing, USA.

BACKGROUND: Integrating end-of-life care (EOL) education into medical residency programs requires knowledge of what programs currently teach and what residents learn. OBJECTIVE: Evaluate EOL teaching content and practices in internal medicine residency programs and the EOL knowledge of their faculty and residents. DESIGN: An interinstitutional pilot study. We examined patterns of EOL education, discerned from program directors' responses to structured surveys of institutional teaching and evaluation practices, and EOL knowledge, derived from the performance of faculty and residents on a 36-item knowledge examination. SUBJECTS: Program directors, faculty, and residents at 32 accredited U.S. internal medicine residency programs. RESULTS: Although all programs cited inclusion of some EOL education, expected EOL domains were not systematically taught or assessed. Pain assessment and treatment training was required in only 60% of programs. Even fewer programs required instruction on nonpain symptoms (<30%) or hospice and nonhospital care settings (22%). EOL assessment depends primarily on faculty's general ratings of residents' global competency; few programs use knowledge examinations or structured skill assessments. Directors identified barriers and support for improving education. On the knowledge examination, the mean score of residents increased across training levels ($F = 21.7$, $p < .001$), and the mean score of faculty was higher than residents' (57.6%: 48.9%, $t = 51.6$, $p < .001$). CONCLUSIONS: Existing internal medicine residency education lacks training in critical EOL care domains. Residency programs need additional training for residents and teaching faculty in EOL content and skills, with assessment practices that demonstrate competencies have been acquired. Program directors perceive institutional support for making these changes.

Publication Types:

Multicenter Study

PMID: 12353495 [PubMed - indexed for MEDLINE]

63: J Palliat Med 2002 Aug;5(4):497-506

End-of-life curriculum reform: outcomes and impact in a follow-up study of internal medicine residency programs.

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BACKGROUND: In 1998 we initiated a pilot project to evaluate the feasibility of

recruiting and training internal medicine residency programs in methods designed to enhance and integrate end-of-life (EOL) instruction and assessment into their curriculum. OBJECTIVE: To evaluate participants' assessment of the training program and the 12-month impact of the training on the 32 residency programs' EOL teaching. DESIGN: Prospective multi-institutional study. MEASUREMENT AND RESULTS: After participating in training, all participants agreed/strongly agreed that the skills-related objectives of the training were met. Mean ratings of intention to continue with the program were consistent across trainees representing different academic ranks ($F = 2.8$, $p = 0.07$), levels of experience in EOL education ($F = 1.3$, $p = 0.28$), and involvement in other national EOL training programs ($F = 1.5$, $p = 0.23$). Twelve months after training, most programs (78%) continued with the project and had initiated EOL curriculum reform in seven key EOL domains.). CONCLUSIONS: The study suggests that focused training in EOL teaching methods and institutional change strategies can facilitate EOL curriculum reform.

Publication Types:

Evaluation Studies

Multicenter Study

PMID: 12353496 [PubMed - indexed for MEDLINE]

64: J Palliat Med 2002 Aug;5(4):515-29

Care after the onset of serious illness: a novel claims-based dataset exploiting substantial cross-set linkages to study end-of-life care.

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To date, there has not been a study using a large, nationally representative group of patients with serious illness who are at risk for hospice use and who are followed forward in time to understand the determinants of hospice use. In this paper, we outline the development of a large new cohort of 1,221,153 Medicare beneficiaries newly diagnosed with 1 of 13 serious conditions in 1993, a cohort that can be used to study end-of-life care in the United States. In describing our methods, we illustrate the possible utility of Medicare claims for end-of-life research. The members of our cohort are followed forward for hospice and other health care use through December 1997, and for mortality through June 1999. Medicare claims data on their inpatient and outpatient hospital use is also collected. Based on the ZIP Codes and counties in which cohort members lived, we were also able to characterize the health care markets of cohort members, as well as obtain other socioeconomic information about them. Information about cohort member's health care providers is also available. Detailed health information about cohort members' spouses was also collected. We conclude by highlighting the types of analyses that can be conducted in this data set.

PMID: 12243676 [PubMed - indexed for MEDLINE]

65: J Palliat Med 2002 Aug;5(4):531-8

Disease-specific patterns of hospice and related healthcare use in an incidence cohort of seriously ill elderly patients.

Iwashyna TJ, Zhang JX, Christakis NA.

Department of Medicine, Hospital of the University at Pennsylvania, Philadelphia, Pennsylvania, USA.

There appears to be significant heterogeneity across diseases in their patterns of health care use at the end of life. We use a new, nationally representative sample of patients diagnosed in 1993 with 13 serious diseases to demonstrate this variation in rates of inpatient, outpatient, and hospice utilization. The

diseases are: cancer of the lung, colon, pancreas, urinary tract, liver or biliary tract, head or neck, or central nervous system, as well as leukemia or lymphoma, stroke, congestive heart failure, hip fracture, or myocardial infarction. We present disease-specific rates of: length of stay, interhospital transfer, outpatient visits in the year before and 3 years after diagnosis, death within 4 years, and gender-specific hospice use rates among decedents. Among decedents with noncancer diagnoses, rates of hospice use vary from 5.9% to 8.7%. Among decedents with cancer diagnoses, rates vary from 15.2% to 35.2%. For the cohort overall, 14.2% of male decedents and 12.4% of female decedents used hospice. Patterns of end-of-life care vary substantially according to diagnosis. PMID: 12243677 [PubMed - indexed for MEDLINE]

66: J Palliat Med 2002 Aug;5(4):553-8

The Louisiana State Penitentiary: Angola prison hospice.

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Louisiana State Penitentiary (Angola) has a large population of aging men serving long sentences with little hope of reprieve. Eighty-five percent of the 5108 inmates currently incarcerated at Angola are expected to die there. The prison, in partnership with University Hospital Community Hospice in New Orleans, has created a program that meets criteria set by the National Hospice and Palliative Care Organization for community hospice programs. The hospice was developed and services are delivered without additional cost to the prison. Consultation, training and support have been provided by the community hospice. Care is provided within the prison infirmary, by prison staff and inmate volunteers.

PMID: 12243680 [PubMed - indexed for MEDLINE]

67: J Palliat Med 2002 Aug;5(4):549-52

Hospice care for the incarcerated in the United States: an introduction.

Linder JF, Enders SR, Craig E, Richardson J, Meyers FJ.

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Prison populations throughout the United States are growing; the 1990s saw an average 6.5% per year increase. Average inmate age is increasing, as are both the number and rate of inmate deaths. Aging inmates experience health concerns typical of the general, free, aging population. Inmates have higher incidence of health complications associated with various circumstances, risk behaviors, and associated medical conditions. These circumstances include prison violence, incarceration-related constraints on exercise, and diet. Inmates are more likely to have a history of alcohol abuse, substance abuse or addiction and sex industry work. Risk-behavior conditions include human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), hepatitis B and C, liver disease, tuberculosis, endocarditis, and cardiomyopathy. Hospice is increasingly the preferred response to the health and care needs of terminally ill inmates. Implementing hospice behind bars has some unique challenges in addition to those inherent in hospice work. This series will provide an in-depth look at four hospice programs for inmates in the United States.

PMID: 12243679 [PubMed - indexed for MEDLINE]

68: J Palliat Med 2002 Aug;5(4):617-21

Clinical pathways for care of the dying: an innovation to disseminate clinical excellence.

Ellershaw J.

Publication Types:

Editorial

PMID: 12243687 [PubMed - indexed for MEDLINE]

69: J Palliat Med 2002 Aug;5(4):623-33

Developing an integrated Department of Pain and Palliative Medicine.

Portenoy R, Heller KS.

Department of Pain Medicine and Palliative Care, Beth Israel Medical Center, New York, New York 10003, USA. RPortenoy@bethisraelny.org

Publication Types:

Interview

PMID: 12243688 [PubMed - indexed for MEDLINE]

70: J Palliat Med 2002 Aug;5(4):475-81

Advance care planning is not about "getting it right".

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PMID: 12243673 [PubMed - indexed for MEDLINE]

71: J Palliat Med 2002 Aug;5(4):635-44

Raising the standard of care for imminently dying patients using quality improvement.

Bookbinder M, Romer AL.

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Publication Types:

Interview

PMID: 12243689 [PubMed - indexed for MEDLINE]

72: J Palliat Med 2002 Aug;5(4):571-3

When the prognosis leads to indifference.

Fins JJ, von Gunten C.

Division of Medical Ethics, Department of Public Health, Weill Medical College of Cornell University, New York, New York 10021, USA.

jjfins@mail.med.cornell.edu

PMID: 12243684 [PubMed - indexed for MEDLINE]

73: J Pastoral Care Counsel 2002 Fall;56(3):221-5

Depth oriented brief therapy: an ideal technique as hospice lengths-of-stay continue to shorten.

Thomson JE, Jordan MR.

Merrimack Valley Hospice, 360 Merrimack St., Bldg. 9, Lawrence, MA 01843, USA.

The authors note that as hospice patients' lengths-of-stay continue to shorten, psychosocial/spiritual counselors are being challenged to help patients and families process the myriad of issues terminal illness gives rise to. Given this reality, the authors suggest that the Depth Oriented Brief Therapy (DOBT) approach should prove especially useful. The DOBT premise is that if people can be helped to experience the emotional meanings of why they hold on to emotionally painful symptoms then they can abandon their symptoms for healthier ways of being.

PMID: 12385135 [PubMed - indexed for MEDLINE]

74: J Pediatr Nurs 2002 Dec;17(6):456-9
End-of-life care: A priority issue for pediatric nurses.
Bowden VR.
Vicky Bowden, RN, DNSc, Azusa Pacific University, 901 E. Alosta Ave. Azusa, CA
91702-7000.
PMID: 12518287 [PubMed - in process]

75: J R Soc Med 2002 Nov;95(11):529-30
Comment on:
J R Soc Med. 2002 Nov;95(11):536-8.
Upstream from death.
Kite S.
Publication Types:
Comment
Editorial
PMID: 12411614 [PubMed - indexed for MEDLINE]

76: J R Soc Med 2002 Nov;95(11):536-8
Comment in:
J R Soc Med. 2002 Nov;95(11):529-30.
What happens when elderly people die?
Kafetz K.
Department of Medicine for Elderly People, Whipps Cross University Hospital,
Whipps Cross Road, London E11 1NR, UK. kalman.kafetz@whippsx.nhs.uk
Publication Types:
Review
Review, Tutorial
PMID: 12411616 [PubMed - indexed for MEDLINE]

77: J R Soc Med 2002 Nov;95(11):565-6
The law on dying.
Hamilton R.
Guy's, King's and St Thomas's School of Medicine, Commonwealth Hall, Cartwright
Gardens, London WC1H 9EB, UK. Richard.Hamilton@kcl.ac.uk
Publication Types:
Legal Cases
PMID: 12411629 [PubMed - indexed for MEDLINE]

78: JAMA 2003 Jan 1;289(1):96
MSJAMA. Advance directives and patient-physician communication.
Hahn ME.
Weill Medical College of Cornell University, New York, NY, USA.
PMID: 12503989 [PubMed - indexed for MEDLINE]

79: JAMA 2002 Dec 4;288(21):2732-40
Withdrawal of life support: intensive caring at the end of life.
Prendergast TJ, Puntillo KA.
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The technology and expertise of critical care practice support patients through
life-threatening illnesses. Most recover; some die quickly; others, however,
linger--neither improving nor acutely dying, alive but with a dwindling capacity
to recover from their injury or illness. Management of these patients is often
dominated by the question: Is it appropriate to continue life-sustaining

therapy? Patients rarely participate in these pivotal discussions because they are either too sick or too heavily sedated. As a result, the decision often falls to the family or the surrogate decision maker, in consultation with the medical team. Decisions of such import are emotionally stressful and are often a source of disagreement. Failure to resolve such disagreements may create conflict that compromises patient care, engenders guilt among family members, and creates dissatisfaction for health care professionals. However, the potential for strained communications is mitigated if clinicians provide timely clinical and prognostic information and support the patient and family with aggressive symptom control, a comfortable setting, and continuous psychosocial support. Effective communication includes sharing the burden of decision making with family members. This shift from individual responsibility to patient-focused consensus often permits the family to understand, perhaps reluctantly and with great sadness, that intensive caring may involve letting go of life-sustaining interventions.

PMID: 12460097 [PubMed - indexed for MEDLINE]

80: Lancet 2002 Dec 21-28;360(9350):1997-8

Comment on:

Lancet. 2002 Dec 21-28;360(9350):2026-30.

Death and dignity: dogma disputed.

Agrawal M, Emanuel E.

Department of Clinical Bioethics, Warren G Magnuson Clinical Center, National Institutes of Health, Bethesda, MD 20892, USA. agrawalm@mail.nih.gov

Publication Types:

Comment

PMID: 12504390 [PubMed - indexed for MEDLINE]

81: Med Care 2002 Dec;40(12):1133-5

Comment on:

Med Care. 2002 Dec;40(12):1136-48.

Lessons from the end of life in the program of all-inclusive care of the elderly.

Lynn J.

Publication Types:

Comment

Editorial

PMID: 12458296 [PubMed - indexed for MEDLINE]

82: Med Care 2002 Dec;40(12):1136-48

Comment in:

Med Care. 2002 Dec;40(12):1133-5.

Health care services utilization at the end of life in a managed care program integrating acute and long-term care.

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BACKGROUND: The period preceding death is often characterized by increased utilization of medical resources. There is an ongoing debate on the reasons for and the appropriateness of increased utilization at the end of life. OBJECTIVES:

To study end-of-life practices in the PACE program and to assess the

contribution of individual characteristics versus program site to the variation

in use of services. RESEARCH DESIGN: Retrospective analyses of utilization and

health status data for the last 3 years before death. Multivariate regression techniques were used to estimate models predicting utilization of services and the percent of variation explained by individual characteristics and program sites in relation to time from death. SUBJECTS: The study comprised 2160 persons enrolled in 10 PACE sites who died before 2000. MEASURES: Monthly utilization by service type (eg, hospital, nursing home, primary care physicians), socioeconomic, and health status data. RESULTS: Utilization of health services increases as early as 7 months before death, with the largest increase in the last month. The increase is dominated by hospital use. During the last month before death variation across program sites explains twice as much of the variation in service utilization as does variation in individual characteristics. CONCLUSIONS: The variation in end-of-life practices across PACE program sites, which are not attributed to differences in individual characteristics, raises two important questions: what are the causes for these variations; and are these variations desirable? Further research is required to answer both questions.
PMID: 12458297 [PubMed - indexed for MEDLINE]

83: Ment Disabil Law Rep 2001 Nov-Dec;25(6):920
Living will; nutrition, hydration; persistent vegetative state; clear and convincing evidence.
Publication Types:
Legal Cases
PMID: 12426704 [PubMed - indexed for MEDLINE]

84: Mod Healthc 2002 Dec 2;32(48):16
Room for improvement. Report: access to hospice, palliative care 'mediocre'.
Piotrowski J.
Publication Types:
News
PMID: 12510628 [PubMed - indexed for MEDLINE]

85: N Engl J Med 2002 Dec 19;347(25):2082-3; author reply 2082-3
Comment on:
N Engl J Med. 2002 Aug 22;347(8):582-8.
Nurses' and social workers' experience with patients who requested assistance with suicide.
Polowetzky D.
Publication Types:
Comment
Letter
PMID: 12494939 [PubMed - indexed for MEDLINE]

86: N Engl J Med 2002 Dec 19;347(25):2082-3; author reply 2082-3
Comment on:
N Engl J Med. 2002 Aug 22;347(8):582-8.
Nurses' and social workers' experience with patients who requested assistance with suicide.
Haley WE, McMillan SC, Schonwetter RS.
Publication Types:
Comment
Letter
PMID: 12490697 [PubMed - indexed for MEDLINE]

87: Nurs Stand 2002 Oct 30-Nov 5;17(7):83
Life and death issues. Interview by Alison Moore.
Musgrave S.
Publication Types:
Interview
PMID: 12452096 [PubMed - indexed for MEDLINE]

88: Nurs Times 2002 Nov 26-Dec 2;98(48):22-5
When the truth hurts.
Whyte A.
PMID: 12501522 [PubMed - indexed for MEDLINE]

89: Oncol Nurs Forum 2003 Jan-Feb;30(1):E1-E11
The role of oncology nursing to ensure quality care for cancer survivors: a report commissioned by the national cancer policy board and institute of medicine.
Ferrell BR, Virani R, Smith S, Juarez G.
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PURPOSE: To examine the roles of oncology nurses in improving quality care for cancer survivors. DATA SOURCES: A content analysis of textbooks, journals, and key documents; surveys of graduate oncology nursing programs and the Oncology Nursing Society's Survivorship Special Interest Group; review of the nursing licensure examination and oncology nursing certification; review of undergraduate and graduate nursing standards; and review of currently funded nursing research. DATA SYNTHESIS: Ten critical content areas of cancer survivorship were used for the analysis: description of population of cancer survivors, primary care, short- and long-term complications, prevention of secondary cancer, detecting recurrent and secondary cancers, treatment of recurrent cancer, quality-of-life issues, rehabilitative services, palliative and end-of-life care, and quality of care. Although findings within each source indicated significant information related to the roles of nurses in caring for cancer survivors, deficits also were identified. CONCLUSIONS: Review of key literature and resources suggests significant contributions by oncology nursing over the past two decades to the area of cancer survivorship. IMPLICATIONS FOR NURSING: Support is needed to expand education and research to ensure quality care for future cancer survivors.
PMID: 12515992 [PubMed - in process]

90: Oncol Nurs Forum 2003 Jan-Feb;30(1):35-50
Palliative and End-of-Life Care: Policy Analysis.
Reb AM.
College of Nursing, University of Maryland, Baltimore, MD, USA. amrreb@aol.com
PURPOSE/OBJECTIVES: To present an overview of policy issues affecting hospice and palliative care focusing on the nursing home and hospital settings and to discuss factors affecting end-of-life care, policy initiatives, recent legislation, and nursing implications. DATA SOURCES: Published articles; technical, advisory, and research reports (from government, professional, and private organizations); newsletters; textbooks; meeting minutes; online references; and legislative documents. DATA SYNTHESIS: Improvements are needed in end-of-life care, especially with regard to access, delivery, and financing of such services. Legal, organizational, and reimbursement policies, as well as healthcare professional education, have been identified as areas that need

improvement. The nursing shortage and variable reimbursement policies for nursing services have a significant impact on access to quality end-of-life care, especially for underserved populations. CONCLUSIONS: A need exists for further research, including demonstration projects to test new ways to deliver and integrate hospice and palliative care throughout the illness continuum. Education and research are needed regarding symptom management, communication and decision making, caregiver support, and other end-of-life issues. Nursing interventions, palliative care networks, and other models that promote a coordinated approach to care delivery have been shown to decrease costs and improve quality of care. IMPLICATIONS FOR NURSING: Nurses play a key role in advancing improvements in palliative and end-of-life care through their involvement in educational, quality improvement, research, and legislative initiatives. Nursing activities in these areas may contribute to improved access, lower costs, and improved quality of care in advanced illness. PMID: 12515982 [PubMed - in process]

91: Pain Manag Nurs 2002 Dec;3(4):154-60

The language of pain at the end of life.

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The effective management of pain at the end of life relies on the accurate assessment of pain. Language is the mechanism through which pain is assessed using self-report pain tools. The purpose of this study was to explore how elderly hospice patients describe their pain and to compare their descriptions with three commonly used pain assessment tools (i.e., McGill Pain Questionnaire, Memorial Pain Assessment Card, and the Visual Analogue Scale). Eleven elderly hospice patients with cancer were interviewed in their homes using open-ended unstructured questions. Data were analyzed line by line to identify descriptors of pain. These descriptors were then compared to standardized language used in the three pain assessment tools. In describing their pain, participants used many words, emphasized their pain by repeating those words, and used similes to describe their pain. The participants used approximately 30% of the standardized language found in three commonly used self-report instruments. These findings suggest that in conjunction with self-report instruments, the patient's own verbal descriptions should be used in the assessment of pain. Copyright 2002 by the American Society of Pain Management Nurses
PMID: 12454807 [PubMed - indexed for MEDLINE]

92: Palliat Med 2001 Nov;15(6):522

The prescription of steroids in the terminal phase.

Gannon C.

Publication Types:

Letter

PMID: 12403514 [PubMed - indexed for MEDLINE]

93: Palliat Med 2001 Nov;15(6):513-4

Palliative care involvement in patients stopping haemodialysis.

Rich A, Ellershaw J, Ahmad R.

Royal Liverpool University Hospital, UK.

PMID: 12403510 [PubMed - indexed for MEDLINE]

94: Palliat Med 2001 Nov;15(6):481-6

The concept of palliative care in The Netherlands.

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Palliative care in The Netherlands is growing and the climate for further development is favourable. Although there is a great deal of consensus on the current debates within palliative care, important disagreements persist. These disagreements relate to the history of palliative care within the country, the scope of palliative care, its values, the appropriate institutional context, and the moral acceptability of euthanasia in palliative care. In this paper, the consensus and the disagreements are described and discussed. It is concluded that many disagreements emerge from so-called external goals of palliative care. It is recommended that the debate should refocus on the internal goal of palliative care, which is the quality of life of the patient and his or her loved ones.

PMID: 12403505 [PubMed - indexed for MEDLINE]

95: Palliat Med 2001 Nov;15(6):471-80

The emergence of Medicare hospice care in US nursing homes.

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Although Medicare-financed hospice care has been provided in nursing homes in the USA for over 10 years, very little is known regarding the use of this government health care benefit in nursing homes. Using resident assessment data and hospice and inpatient Medicare claim data from five US states, we were able to identify and describe nursing home residents receiving hospice care between 1992 and 1996, and their hospice utilization patterns. Six per cent of all dying nursing home residents received hospice care at some point in time and, in 1996, an estimated 24% of all Medicare hospice patients in the five study states received hospice while in a nursing home. Of those residents beginning hospice care after nursing home admission, 48% were 85 years or older, 70% were female, 94% were white, 76% were unmarried and 62% had a non-cancer principal diagnosis.

The average length of stay in the hospice programme for residents receiving hospice care while in the nursing home was 90.6 days, the median 35 and the mode 2. Hospice care in US nursing homes is a prevalent model of care that appears further to extend the Medicare hospice benefit to older adults who are female and to those with non-cancer diagnoses. Lengths of stay in the programme are similar to those observed in the community and the average length of stay is substantially shorter than previously estimated by an influential government study.

PMID: 12403504 [PubMed - indexed for MEDLINE]

96: Palliat Med 2001 Nov;15(6):449-50

Comment in:

Palliat Med. 2002 Nov;16(6):549.

Recent guidance on resuscitation: patients' choices and doctors' duties.

Randall F.

Publication Types:

Editorial

PMID: 12403501 [PubMed - indexed for MEDLINE]

97: Palliat Med 2001 Nov;15(6):505-11

Euthanasia: moral paradoxes.

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Over the past 30 years, euthanasia has been under continuous debate in The Netherlands. This contribution aims to provide a moral assessment of this debate. It is argued that euthanasia should be understood within a historical context, as a protest against medical power and as a way to bring about good death. Within the euthanasia debate, two paradoxes are identified which make the issue inherently complex and hard to regulate. The first paradox results from the dialectical relation between individual autonomy and relief of suffering as the major justifications of euthanasia. Although euthanasia represents an ultimate effort to give the individual patient control over his dying, the result of the debate is an increase of medical power. The second paradox is that although euthanasia emerged from a commitment to good death, it is resulting in a reduced range of options to bring about good death.

PMID: 12403509 [PubMed - indexed for MEDLINE]

98: RN 2002 Nov;65(11):51-4

Less morphine, or more?

Perkins EM.

Genesee Region Home Care, Rochester, N.Y., USA.

PMID: 12465527 [PubMed - indexed for MEDLINE]

99: Soc Sci Med 2003 Jan;56(1):95-109

Judging the quality of care at the end of life: can proxies provide reliable information?

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A major challenge in research into care at the end of life is the difficulty of obtaining the views and experiences of representative samples of patients. Studies relying on patients' accounts prior to death are potentially biased, as they only represent that proportion of patients with an identifiable terminal illness, who are relatively well and therefore able to participate, and who are willing to take part. An alternative approach that overcomes many of these problems is the retrospective or 'after death' approach. Here, observations are gathered from proxies, usually the patient's next of kin, following the patient's death. However, questions have been raised about the validity of proxies' responses. This paper provides a comprehensive review of studies that have compared patient and proxy views. The evidence suggests that proxies can reliably report on the quality of services, and on observable symptoms. Agreement is poorest for subjective aspects of the patient's experience, such as pain, anxiety and depression. The findings are discussed in relation to literature drawn from survey methodology, psychology, health and palliative care. In addition to this, factors likely to affect levels of agreement are identified. Amongst these are factors associated with the patient and proxy, the measures used to assess palliative care and the quality of the research evaluating the validity of proxies' reports. As proxies are a vital source of information, and for some patients the only source, the paper highlights the need for further research to improve the validity of proxies' reports.

Publication Types:

Review

Review, Academic
PMID: 12435554 [PubMed - indexed for MEDLINE]

100: Spinal Cord 2002 Nov;40(11):581-94

Awareness and use of advance directives in the spinal cord injured population.

Blackmer J, Ross L.

Division of Physical Medicine and Rehabilitation, University of Ottawa, Ottawa, ON K1H 8M2, Canada.

STUDY DESIGN: Research was conducted through the use of semi-structured patient interviews. Subjects were recruited through the Saskatchewan branch of the Canadian Paraplegic Association (CPA) and through the clinical practice of the primary investigator. A total of twenty-one patients were interviewed. A

qualitative outcome analysis was performed on information collected. **OBJECTIVES:**

Advance directives (or living wills) serve to communicate the wishes of individuals in the event that they should no longer be capable of making those wishes known. This can include directives on issues such as resuscitation status and withdrawal or withholding of care. The goal of this study was to determine the present level of knowledge and interest of spinal cord injured (SCI) patients on the topic of advance directives, and to determine what specific issues they felt need to be addressed in such a document in this population.

SETTING: The study was performed in Saskatoon, Saskatchewan, Canada. Although design and analysis were done in a tertiary care centre, the interviews

themselves were conducted in the homes of the participants. **RESULTS AND**

CONCLUSION: The results show that spinal cord injured patients have some knowledge of what is involved in the preparation of an advance directive and that they feel these documents are important. A relatively small percentage have completed their own written directives but a large percentage planned to do so after completing this survey. There is some disagreement about when after the injury the topic should first be discussed. Information about medical conditions which are more likely to arise following a SCI should be included in an SCI-specific document. A template for an SCI-specific living will (the SCIAD) is provided.

PMID: 12411966 [PubMed - indexed for MEDLINE]

101: Support Care Cancer 2002 Sep;10(6):474-9

Fluid status of terminally ill cancer patients with intestinal obstruction: an exploratory observational study.

Morita T, Tei Y, Inoue S, Suga A, Chihara S.

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Although the dehydration-rehydration problem in end-of-life care is one of the most important issues, clinical indications of hydration therapy have not been clarified because the pathophysiology is poorly understood. To explore the physiological changes of fluid status in terminally ill cancer patients, a prospective observational study was performed. We obtained 9 pairs of blood samplings from hospice inpatients with irreversible bowel obstruction who underwent two or more laboratory examinations during the admission periods. The plasma renin activity (PRA) and brain natriuretic peptide (BNP) were measured, in addition to basic laboratory tests performed as clinically required. A chart review evaluated the degree of fluid retention symptoms. In 7 patients receiving intravenous rehydration of 700-2200 ml/day, the mean PRA level significantly increased from 3.5 ± 2.5 ng ml⁻¹ h⁻¹ to 11 ± 8.2 ng ml⁻¹ x h⁻¹ (P=0.047), and the mean BNP level significantly decreased from 52 ± 34 pg/ml to 22 ± 14 pg/ml (P=0.047). Edema, ascites, and pleural effusion/pulmonary edema

deteriorated in 5, 3, and 5 patients, respectively. In 2 patients without rehydration therapy, peripheral edema deteriorated with increased PRA levels (0.5 to 20 ng ml⁻¹ x h⁻¹), 0.4 to 8.7 ng ml⁻¹ x h⁻¹, respectively). In conclusion, intravenous volume depletion with fluid retention symptoms was observed in terminally ill cancer patients with intestinal obstruction both receiving and not receiving intravenous hydration. The pathological mechanism hypothesized is the fluid shift from the intravascular compartment to the interstitial spaces.

PMID: 12353126 [PubMed - indexed for MEDLINE]